

Chronic Illness Wisdom is Both/And

by Carmen Cutler | Issue 11.2 (Fall 2022), Crip Pandemic Life: A Tapestry

ABSTRACT This poem reflects on dual tensions that sick & disabled communities have to navigate during ongoing pandemic conditions. In particular, it addresses the chronic illness knowledges that people with post-viral illnesses already possess (the reality of chronic conditions after acute infections, the necessity of solidarity across bed space) in the face of medical and political institutions that refuse to know.

KEYWORDS disability, knowledge, pandemic, chronic illness, bed space, post-viral

To live with dysautonomia or ME or long
covid or a myriad of chronic illnesses is to
already know, to repeatedly sound
the alarm, that viruses are not
an either/or matter of
recovery or death

and yet have health systems, policies, and
official numbers continuously fail to reflect
what we know, what we've lived in the
both/and land of post-viral illness.

We know what it's like to make it through
an infection

and still remain sick, year after year.

In any viral outbreak, we know to expect
5%, 10%, 20% of those infected

to "recover"

and yet never recover.

We know that 5%, 10%, 20% of a population
is both small

and enormous.

Small enough to make you think
it will never happen to you

and enormous enough to engulf
the millions missing.

This is known. For decades, we've written it,
shouted it, marched for it,
cared for each other through it

and yet it is unknown, a parade of shocked
journalists and clinicians and researchers and
public health officials who refuse to know.

We're learning, together, to deeply love
our sick bodyminds

and also would not wish this fatigue
on anyone.

We know how vital it is to slow down, to
rest, our bodyminds show the signs

and we know how capitalism shreds the
possibilities for it.

We know what it feels like to be
simultaneously more isolated

and more connected with our disability
community.

We know this is nothing new, we've been
connecting across time and space from
our couches and beds for years

and yet this time requires nimble ways to
navigate new waves of old grief.

In it all we hold deep grief for loss of life

and deep solidarity with the hundreds-
thousands-millions who are now starting
their chronically ill lives.

Artist's Statement

Living through an ongoing pandemic era highlights the knowledges that disabled people already have, which are not acknowledged in public health responses, nor in public discourse. From the first weeks of this pandemic, chronically ill communities already knew that it would be a mass disabling event, adding to the already existing necropolitical processes of debility¹—from the impacts of climate disaster to chemical injury from environmental toxicities within geographies of racial capitalism. Chronically ill community knowledges are a vital resource for the newly disabled. Disabled people with post-viral illness(es) already know the deep value of rest; the indispensability of collective grieving processes and of connecting with each other across bed space(s) for survival and crip joy.²

In collecting my thoughts for this piece, I turned to a both/and approach as a way of thinking that has the capacity to hold tensions without breaking.³ The context of the COVID pandemic illustrates a both/and that we are required to dwell in—resisting the violence of the Medical Industrial Complex while also fighting for increased access to medical resources. "Chronic Illness Wisdom is Both/And" in essence argues that chronic illness communities are particularly well-practiced in this approach, by necessity.

So often, chronically ill people as a whole are relegated outside a collectively presumed “we”—particularly in public discourse around severe illness and death risk from COVID, the chronically ill are the “them” to the presumed “us” of ableist society: Our “we” is sequestered from the general body politic, and made invisible by dominant narratives that refuse to consider disability as a fact of life. Both as a way to imagine a different kind of public and to resist individualized narratives about chronic illness, I intentionally use the word “we” in this piece instead of “I.” I use “we” to recognize a public that knows chronic illness as multiple, overlapping, nuanced experiences within an array of social locations, recognizing that ableism is distributed unevenly across race, geography, class, and myriad combinations of systems of oppression. In the face of negligence, refusal of care, and political erasure, I invoke a public comprised of sick and disabled communities, a body politic whose knowledge is crucial for collective change and our own crip futures.

Visual Description

The poem is divided into two columns. Each sentence begins in the left column as right justified text. As soon as the word “and” occurs, the sentence shifts to the right column as left justified text. This is to create a push and pull, like a balance scale with the word “and” as a fulcrum. The meanings in each sentence teeter totter to capture the tensions between community knowledge and conflicting ableist norms.

Notes

1. Jasbir Puar, *The Right to Maim: Debility, Capacity, Disability* (Durham, NC: Duke University Press, 2017). ↩
2. Ronak K. Kapadia, Patrisia Macías-Rojas, Akemi Nishida, Monica Cosby, Pato Hebert, Aurora Levins Morales, and Dean Spade, “The Reciprocal Politics of Bed Space Activism: Creative Resistance and Radical World Making,” March 11, 2022, UIC Institute for the Humanities, YouTube, 1:25:54, <https://www.youtube.com/watch?v=yHO26DZAqUI>. ↩
3. Mia Mingus, Talila Lewis, Liat Ben-Moshe, and Connie Wun, “Disability Justice, COVID, and Abolition (an ASA 2020 Freedom Course),” American Studies Association Official, November 15, 2020, YouTube, 1:07:13, <https://www.youtube.com/watch?v=r4OKA2nKGC8>. ↩

Author Information

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Carmen Cutler is a sick and disabled doctoral candidate at the University of Illinois at Chicago. Her work focuses on the lived experiences of sick and

disabled communities, and their knowledges both personal and political, embedded in long histories of community resistance against the violence and neglect of medical institutions.

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Article details

Carmen Cutler, "Chronic Illness Wisdom is Both/And," *Lateral* 11.2 (2022).

<https://doi.org/10.25158/L11.2.17>

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ISSN 2469-4053